

Maternal Role in Guiding Social Communication to Autistic Children as a Quality of Life Determinant

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ABSTRACT

Background: Autism spectrum disorder is a type of neural development disorder. It is characterized by deficit in social communication, social interaction, and repetitive behavior pattern. It is assumed that maternal role in child education is more dominant than paternal role, because children are closer to their mothers since birth. It is also assumed that the quality of life of autistic children would improve if there is improvement in their social communication and social interaction. This study aimed to examine the maternal role in guiding social communication to autistic children as a determinant of child quality of life.

Subjects and Method: This was a qualitative study conducted in public special school in Tangerang District, West Java, from October to December 2017. Informants for this study included 5 mothers of autistic children and 3 teachers-therapists at the public special school. The constructs under study included maternal role in guiding social communication and social interaction in autistic children. The data were collected by in-depth interview, observation, and document review. The data were analyzed by Miles and Huberman method.

Results: Mothers had an important role in observing various child behaviors, seeking advice from expert, determining child development need, exploring child sensory-dietary-medical need at home. Other maternal roles included admitting children to primary school or special school that was suitable for child potential development and involving children in simple daily activities at home. The maternal role in guiding social communication was considerably good including communication therapy at home using audio visual aids, stimulating oral motoric skill, providing social interaction therapy by story telling, teaching socialization to children by familiarizing them to greet and handshake with others, and letting them to play with other children. The maternal role in improving quality of life was sufficiently good, so that each child was able to develop their communication and interaction skills with varying levels of improvement.

Conclusion: Maternal role in guiding social communication in autistic children is sufficiently good although there is a need to improve its implementation in order to gain improved quality of life. It is advisable for mothers to carry on guiding program at home so as to develop child potentials and to reduce their weak aspects.

Keywords: maternal role, guiding, communication, quality of life, autistic children

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BACKGROUND

The estimation of people with autism in the world is 1 among 160 children (World Health Organization, 2016). The number of children affected by autism is increasing rapidly in various parts of the world. UNESCO (2011) reported that there are 35

millions people with autism worldwide. This means that approximately 6 out of 1,000 people in the world suffer from autism (Hasnita E and Hidayati R, 2015). Data from the Center of Disease Control (CDC) in the "Community Report on Autism 2016", the prevalence of autism in

America is 1 out of 68 children or 1.5% of children aged 8 years (Centers for Disease Control and Prevention United States, 2016).

Currently, in Indonesia there is no statistical data on the number of people with autism, but it is expected to increase. This can be seen from the number of visits in public hospitals, mental hospitals at children's clinics which grow significantly meaningful from year to year (Ministry of Health, 2016).

Banten Province is administratively divided into 4 districts (Pandeglang, Lebak, Tangerang and Serang) and 4 urban areas (Tangerang, Cilegon, Serang and South Tangerang). The population of Banten in 2017 is the fifth and the third most populous population in Indonesia with 12.4 million people. The population of Banten is centered in North Banten (Tangerang Regency, Tangerang City, South Tangerang City). Tangerang Regency is the region with the most population of 3.6 million people (28.8%) (Central Bureau of Statistics of Banten Province, 2017).

The data obtained from each Central Bureau of Statistics (BPS) in the administrative region include the number of children aged 0-14 years in Tangerang regency was 985,648 people (BPS Tangerang District, 2017), the number of children aged 0-14 years in the city of Tangerang was 509,194 (BPS Tangerang City, 2017), the number of children aged 0-14 years in Lebak district was 402,805 (BPS Lebak District, 2017), the number of children aged 0-14 years in the city of South Tangerang was 399,420 (BPS City of South China, 2017), the number of children aged 0-14 years in Pandeglang district was 382,179 (BPS Pandeglang regency, 2017). The number of children aged 0-14 years in Serang district was 229,822 (BPS Serang District, 2017), the number of children aged

0-14 years in the city of Serang was 200,535 (BPS Serang City, 2017), and the number of children aged 0-14 years in the city of Cilegon was 117,557 (BPS Cilegon City, 2017).

The largest number of children in Banten Province is in Tangerang Regency with 985,648 people. WHO (2017) estimates the number of people with autism in the world is 1 in 160 children. Using the comparison, it can be estimated that autistic in Tangerang district was approximately 6,160 people.

Autism spectrum disorder is a neuro-development disorder. This is characterized by social communication deficits and social interactions, and repetitive behavior patterns (Kałużna-Czaplińska, Zurawicz and Józwik-Pruska, 2017).

Autism is a psychological-social disorder in children's development. All of the mentioned symptoms are triads of symptoms of the spectrum of autistic disorders, namely: social interaction disorder, communicative disorder, and apparent behavioral disorder in stereotyped form (Kach-maryk, 2013).

The roles of the mother in the family includes: meeting the physiological and psychological needs of the child, taking care of the family, educating, arranging and controlling the child, giving stimulus (stimulus) and teaching the children (Gunarsa, 2008).

Mother is a life milestone in a family that gives full attention to their children. The role of mothers in the education of children is more important and dominant than the role of the father. This needs to be understood because the mother is the person who has more to accompany her children since a child is born (Gade, 2012).

Quality of life is the level by which individuals can maximize their physical, psychological, vocational, and social

functions. Quality of life is assessed on the basis of individual assessments of individual functions, viewed directly from observations of the performance of individual behavior. All of these functions form a concept of quality of life (Taylor, 2006). The quality of life of an autistic child may increase if the interaction and communication skills are better on the level (Alimin et al, 2009).

Targets behavior at each level of development according to Alimin et al. (2009) are: level 1-children have skills in eye contact and attentions together, level 2-children pointing objects, labeling objects, and doing tasks together, level 3-children growing desire to ask for something desired, and level 4-children have initiative to start interaction and communication.

Based on these problems, this study aims to analyze the role of mothers in social communication coaching children with autism as a determinants improvement in quality of life.

The formulation of this research problem is: how is mothers' roles in autistic children governance? How is the role of mothers in social communication counseling child autistic? How is the role of mothers in improving the quality of life of children with autism? The purpose of this study is to analyze the role of mothers in the guidance of social communication of children with autism as a determinant of quality improvement of life.

SUBJECTS AND METHOD

1. Study Design

This study used a qualitative design. The study was conducted at the State Special School (SKh Negeri) 01 Tangerang Regency.

2. Population and Sample

The number of informants obtained until saturation data was 5 people with autism

children who experienced communication development and 3 therapists who were the teachers at the school.

3. Study Variables

The focus of the problem taken in this research is:

- a. The role of mothers in autistic child governance
- b. The role of mothers in social communication counseling of autistic children
- c. The role of mothers in social communication counseling autistic children

4. Data Collection technique

The data collection techniques were conducted with in-depth interviews, observation and document analysis.

Data collection tools used were when the researcher used interview guides, voice recorder, camera, document needed in research and observation sheets.

Assessment of interaction and communication skills in autistic children using instruments made by the Foundation for Disabled Children Education (2016).

Interviews were conducted to 5 informants (mother) about the initial condition of the children before being diagnosed with autism, then it was analyzed in depth through in-depth interviews, observation of children behavior, and document analysis. An in-depth interview of children's behavior and communication to teachers and mothers were needed to determine the current state of the children related to the level of interaction and communication skills development. Therefore, the increase in the level of interaction and communication of the children can be seen.

5. Data Analysis

In analyzing the data, Miles and Huberman interactive analysis was employed.

6. Research Ethics

The research ethics included Informed Consent, anonymity, confidentiality and ethical clearance. The ethical clearance of

this research was conducted at Dr. Moewardi hospital.

RESULTS

1. Mother role in taking care autistic children

The results of the interviews about the role of mothers in autistic child governance shows that mothers' roles included: observing different children's behavior with other children; consultation with experts (doctors, psychologists, educators) to obtain information, diagnostics and recommendations for further handling. The process done by parents, especially mothers to improve verbal communication in children with autism were: bringing to the doctor, psychologist, kiai, getting the therapy, taking care of the children at home, continuing home therapy program; finding out the needs of the children in accordance with their development, the sensitivity level to the stimulus of motion, sight, hearing, smell, taste and touch like a bigger mouth, training the muscles of the hand to be stronger, teaching to talk in front of mirror, training self-poke, finding out the sensory, dietary, biomedical, and other needs that can be done at home by finding abstinence foods, training the child according to the advice of the therapist, training the child according to the advice of the teacher; experience of incorporating children into public schools; incorporating children into appropriate schools and developing the potential of the children by making them attend some classes such as drawing lessons at school and allowing children to attend ceremonial officers and scouts; involving children in simple activities at home such as washing dishes, watering the plants, sweeping the house, tidying clothes, etc. according to his ability.

2. The role of mothers in social communication counseling autistic children

The results obtained based on the interviews about the role of mothers in the social counseling of autistic children were: the mother acts as a home communication therapist using visual aids with picture cards, blackboards, VCDs; mothers do things that support the mouth motor including giving rough food, asking children to drink with a straw, blowing candles and balloons, training children to make open their mouth bigger; mother acts as a social interaction therapist by storytelling; teaching socialization to children by getting the children to say hello and shake hands with others, and allowing children to play with their peers.

3. The role of mothers in improving the quality of life of children with autism

The results obtained through the interviews, all informants admitted that there was a development of children communication and interaction skills compared to the initial condition of the children.

- a. The child of the informant 1 increased 2 levels from level 1 to level 3
- b. The child of the informant 2 has increased 1 level from level 1 to level 2
- c. The child of the informant 3 increased 3 levels from level 1 to level 4
- d. The child of informant 4 increased 3 levels from level 1 to level 4
- e. The child of informant 5 increased 1 level from level 1 to level 2.

DISCUSSIONS

1. Maternal roles in autistic children's governance

The roles performed by the mothers were:

- a. Observing the different behavior of children. This was done by Inf.1, Inf.2, Inf.3, Inf.4, Inf.5. This was in accordance

with the theory of the Foundation for Disabled Children Education (2016) about the different characteristics of autistic children with their peers.

- b. Consultation with experts (doctors, psychologists, educators) to obtain information, diagnosis, and recommendations for further treatment. Taking the children to see a doctor was done by Inf.1, Inf.2, Inf.3, taking to the kiai done by Inf.4, following the therapy in school before being accepted as the students done by Inf.1, Inf.2, Inf.3, Inf.4, Inf.5, and continued therapy at school conducted by Inf.1, Inf.2, Inf.3, Inf.4, Inf.5.

This is in accordance with the suggestion from the Ministry of Women Empowerment and Child Protection (2013) about the things that should be done by the mother if the child has autism. Similar thing was also expressed by Hadith (2006), who stated that if parents find symptoms of autism in their children, then parents should conduct an early consultation with relevant experts.

- c. Finding out children's needs according to their development, sensitivity to motion, sight, hearing, smell, taste, and touch. This was done by Inf.1, Inf.2, Inf.3, Inf.4, Inf.5
- d. Finding out the sensory, dietary, biomedical and other needs that can be done at home. This was done by Inf.1, Inf.2, Inf.3, Inf.4, Inf.5
- e. The experience in putting the children in public schools. This was done by Inf.3 and Inf.5
- f. Putting the children into the appropriate school, developing the potential of the children. Only Inf.1, Inf.2, and Inf.3 who stated that their children attended drawing lessons after school, Inf.4 said his/her child was being a ceremonial and scout officer, and Inf.5 did not attend

any activities at school. Similar thing also stated by the Foundation for Disabled Children Education (2016), which stated that parents have great responsibility of their children's education, therefore, parents of autistic children must play an active role in developing the children's ability. Schools become agents to encourage children's abilities in academic learning, communication and socialization.

- g. Involving the children in simple home activities, the result obtained that only Inf.5 child who did these simple activities.

2. Maternal roles in guiding social communication to autistic children

The roles performed by the mothers were:

- a. The maternal role as a communication therapist at home by using visual aids. Inf.1 used the books which belong to autistic child's siblings, Inf.2 used picture card, Inf.3 used self-made picture card such as equipment at therapy place, Inf.4 used blackboard as a learning media, Inf.5 used VCD.
- b. Doing things that support mouth motor by giving raw food to the children (Inf.1, Inf.2, Inf.3, Inf.4, Inf.5), asking the children to drink with a straw, blow out the candle, the balloon (only done by Inf.2 and Inf.3), asking the children to open their mouth bigger (Inf.1, Inf.2, Inf.3, Inf.4, Inf.5)
- c. Mother as a social interaction therapist by storytelling was only done by Inf.3.
- d. Teaching about the socialization to children by getting a child to say hello and shake hands with other people and letting them play with peers, this was done by Inf.1, Inf.2, Inf.3, Inf.4, Inf.5.

3. Maternal roles in improving autistic children's quality of life

The children experienced the enhancement by 2 levels, from level 1 to level 3 with the

actions performed by the mother which were: a) water therapy by reciting prayers to the water, then the child drink the water, hugs therapy, when the child was sleeping, the mothers gave some affections by caressing (advice from psychologists), b) Mothers used the sibling's book from autistic children and asked the children to open their mouth bigger, repetition of speech was still done until the children can say it properly, c) Asking the children to write and repeat the lesson that has been delivered at the school, d) Not giving abstinence food to the children, e) Asking the children to play outdoors, f) Providing good food for consumption and avoiding abstinence foods, g) Supporting the children to take drawing lessons at school, h) Praying to Allah SWT.

The children experienced the enhancement by 1 level, from level 1 to level 2 with the actions performed by the mother which were: a) The parents taught the children to multiply the word that was mastered by telling 2-3 times and showed the objects, b) Training children's hands to be stronger using clothes clothesline of different colors (suggestions from classroom teachers), c) Minimize eating abstinence food, d) Using picture cards, e) Training the children to use the word "do not" and "no" because the children cannot refuse when disturbed by their friends (advice from the classroom teachers), f) Asking the children to talk anything and to take things around them, g) Asking the children to play outdoors, h) Providing good food for consumption and avoiding abstinence foods, i) Supporting the children to take drawing lessons at school, j) Praying to Allah SWT.

The development of Inf.3 child was increased by 3 levels, from level 1 to level 4 with the actions performed by the mother which were: a) Mother looking for a nearest

place of therapy which was at Monhal Persada Balaraja Clinic. Take the therapy for about 1 year, before the child was taught to talk, the child was taught to practice concentration by blowing candles, balloons, drinking with straws, blowing paper from small to bigger sizes. b) Put the child into a Playing Group (PG) in Kalimantan for about 5 months, the reason of quitting because there was no significant development in her child, c) Join back the therapy at the Monhal Persada Balaraja Clinic with Mrs. Shella as the therapist for about 10 months, she said the activity was blow exercise started from blowing a small paper, then blowing the bigger paper, the child must also be able to tear the paper from the smallest to bigger sizes. After blowing the paper, they were required to blow a bubble. If they have mastered all the activity, they were required to do speech therapy in front of mirror starting from AIUEO, d) Repeat the therapy performed in the same way that the therapist did, e) Create the similar equipment as in the therapy place, f) Ask for cooperation from other family members when mothers did re-therapy at home, therefore, the situation at home was conducive, g) While on the way, the mother told whatever they met, after they got home, the mother asked the child to repeat the story, h) Follow the advice from the therapist when the child acted uncomfortably by hitting his/her palms to train the reflexes of his/her palms, i) Put the child into Al Izzah Tigaraksa Kindergarten for about 7 months, the reason of quitting was because not being able to follow the lesson and just play in the park, j) Take the child to special school according to Mrs. Shella's suggestion after telling her that the child could not attend in a public school, k) Follow the therapy before accepted in the school for about 1 year, the reason for quitting was because

there was no other programs beside learning to read and write, l) Follow the suggestion from therapist to train a child's motor by playing flour, rice, and sand, m) Ask the children to play outdoors, n) Provide good food for consumption and avoid abstinence foods, o) Support the children to take drawing lessons at school, p) Pray to Allah SWT.

The development of Inf.4 child was increased by 3 levels, from level 1 to level 4 with the actions performed by the mother which were: a) Take the child to an Islam expert for 3 times at 4 years old, given water for her child. The result of Islam expert's therapy was the ability of the child to speak "*mama*", "*Aa*", "*Bapa*", b) Take the 5 years old child to psychologist with a child's IQ examination result of 40 and suffering from autism, c) Follow the therapy at school (before school) with Mr. Y as the therapist for about 6 months, also did massage therapy with Mr. Robert for 3 times to calm the child, then, they stop the therapy because they had no money for child circumcision. Come back to school in June before school enrollment begins, therapy with Mrs R for about 2 months, d) Pay attention to child's dental hygiene (advice from Mr. Robert), e) Teach the children at home by asking the husband to make a blackboard as a medium of learning. The activities taught by mothers were reading the Al-Qur'an, reading books, writing, and drawing, f) Accompany the children to watch TV such as Diva The Series, Ipin and Upin, Okki Setiana Dewi on MNC TV before maghrib pray, g) Implement a suggestion from therapist (Mrs. R) to train the children to defecate and urinate in the bathroom, h) Implement the suggestions from classroom teachers (Mr. D) to let the children to play with their peers at home in order to make children's communication better, i) Accompany the

children while playing outdoors, j) Let the children to become ceremonial officers and scout officers in order to develop their social interaction, k) Provide good food for consumption and avoid abstinence foods, l) Pray to Allah SWT.

The development of Inf.5 child was increased by 1 level, from level 1 to level 2 with the actions performed by the mother which were: a) Take the children into public schools, BR had attended PAUD at the age of 4-5 years old, to Saidah Kindergarten as well as therapy due to the children who did not master some words, b) Take 7 years old child to psychologist as a school enrollment requirement, c) Join the therapy at school (before school) with Mr. Y and Mrs R as the therapists for about 1 year, d) Teach the children at home in terms of communication, reading, and writing, e) Take the child into the special school on the consideration of suggestions from the husband for the child to develop communication and behavior, f) Implement the suggestion from the teacher (Mr. Y) to train the child's communication, for example when the child wanted to drink, they were required to say "drink", g) Let the children to play with their peers at home in order to make children's communication better, h) Provide good food for consumption and avoid abstinence foods, i) Involve the children in simple activity at home, j) Pray to Allah SWT.

Generally, maternal roles in autistic children's governance, guiding social communication, and maternal roles in improving autistic children's quality of life were already good, therefore, all the children experienced development level of interaction and communication skills, although the enhancement of the levels were different, this was because the role of the mother was not too optimal. Mothers should do the program at home conti-

nuously, therefore, the potential of autistic children can be developed and the weakness in children can be eliminated.

REFERENCES

- Alimin Z, Homdijah OS, Sugiarmim M (2009). Meningkatkan Keterampilan Interaksi dan Komunikasi Anak Autistik Melalui Tahapan Perkembangan Interaksi dan Komunikasi Anak Autistik: 27-35
- Badan Pusat Statistik Provinsi Banten. (2017). Statistik Daerah Provinsi Banten Tahun 2017. https://banten.bps.go.id/backend/pdf_publicasi/Statistik-Daerah-Provinsi-Banten-2017.-pdf. Diakses Oktober 2017.
- Centers for Disease Control and Prevention United States (2016). Community Report on Autism 2014. Centers for Disease Control and Prevention, 52. Available at: http://www.cdc.gov/ncbddd/autism/states/comm_report_autism_2014.pdf.
- Gade F (2012). Ibu Sebagai Madrasah Dalam Pendidikan Anak. *Jurnal Ilmiah Didaktika*, 8(1): 31-40.
- Hasnita E, Hidayati R (2015). Terapi Okupasi Perkembangan Motorik Halus Anak Autisme, *Jurnal IPTEK Terapan*, 1(9): 20-27.
- Kachmaryk K (2013). Psychological peculiarities in children with the autistic spectrum disorder, *The Journal of Education Culture and Society*, (2): 162-171. doi: 10.15503/jecs20132-162-171.
- Kałużna-Czaplińska J, Żurawicz E, Jóźwik-Pruska J (2017). Focus on the Social Aspect of Autism. *Journal of Autism and Developmental Disorders*. Springer US: 1-7. doi: 10.1007/s10803-017-3407-7.
- Kementerian Kesehatan (2016). Kenali dan deteksi dini individu dengan spektrum autisme melalui pendekatan keluarga untuk tingkatan kualitas hidupnya. 1-2.
- WHO (2016). Autism spectrum disorders. Available at: <http://www.who.int/mediacentre/factsheets/autism-spectrum-disorders/en/>.